

SURVEY OF ADULT CYSTIC FIBROSIS PATIENTS AND PARENTS OF CYSTIC
FIBROSIS PATIENTS ON NUTRITION EDUCATION

by

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TABLE OF CONTENTS

LIST OF FIGURES.....	iv
CHAPTER1: INTRODUCTION.....	1
Statement of the Problem.....	2
Purpose and Significance.....	2
Hypothesis/Research Questions.....	3
Limitations.....	3
Delimitations.....	3
Assumptions.....	4
Definition of Terms.....	4
CHAPTER II: LITERATUREVIEW.....	5
History.....	5
Malnutrition as a Function of Chronic Illness.....	6
Malnutrition as a Function of Dietary Intake.....	7
Malnutrition as a Function of Mealtime Behavior in Children.....	8
CF Nutrition Programs.....	10
Summary.....	12
CHAPTER III: METHOD.....	14
Participants.....	14
Design.....	15
Measurement Tools.....	15

Procedure.....	15
Statistical Analysis.....	16
CHAPTER IV: RESULTS.....	17
Height, Weight, and BMI.....	17
Weight and Lung Function.....	20
Calorie Intake and Energy Level.....	21
Eating Behaviors.....	23
Weight Maintenance and Growth.....	25
Information Needs Assessment.....	26
CHAPTER V: DISCUSSION.....	30
Conclusion.....	33
REFERENCES.....	35
APPENDIX A.....	39
Recruitment Letter	
APPENDIX B.....	41
Adult Survey	
APPENDIX C.....	45
Parent Survey	
APPENDIX D.....	50
Informed Consent	

LIST OF FIGURES

Figure 1. Mean Responses to Height, Weight, and BMI Questions.....	19
Figure 2. I Am Not Sure Why Knowing BMI is Important.....	20
Figure 3. Mean Responses to Questions Concerning Calories and Energy.....	22
Figure 4. Responses Related to Eating Behaviors in Children.....	24
Figure 5. My Child or I Need to Eat More Salt.....	25
Figure 6. Concerns about Weight for Adults and Parents.....	26

CHAPTER I

Introduction

Cystic fibrosis (CF) is an inherited disorder affecting more than 30,000 Americans, primarily Caucasians (CF Foundation, n.d.a). A defective gene on the seventh chromosome is inherited from the mother and the father. This gene causes the body to produce an abnormal protein that leads to thick, sticky mucus that is secreted by the lungs, pancreas, liver, sweat glands, and reproductive organs. The pancreas normally excretes enzymes that aid in the digestion of food, however this function is impaired in CF, and therefore CF patients must ingest replacement enzymes (CF Foundation, n.d.a). Despite advances in treatment, including replacement enzymes, under-nutrition and impaired growth continue to be significant problems (Stapleton et al., 2000).

Children and adults with CF are instructed by their health care professionals to eat a high calorie (120-150% of the recommended number of calories), high fat (35-40%) diet (Powers & Patton, 2003). Adhering to this recommendation is frequently a challenge for parents of CF children (Stark, 2003). Studies have shown that mealtime behavior problems may be perceived as more intense in CF children than in other children. These problems are identified as "dawdling, refusing and spitting out food, poor appetite, gagging, and mealtime mismanagement by parents" (Stark, 2003, p. 794). However, studies have shown that behavior and nutrition education can have a positive impact on these issues (Powers, Acton, et al., 2005).

Nutrition education is provided at accredited CF clinics (CF Foundation, n.d.b.). Adult and pediatric CF patients are monitored through quarterly visits to their local CF clinic. Growth, nutrition, and respiratory status are recorded and monitored for pediatric patients, and nutrition and respiratory status are recorded and monitored for adult patients. Nutrition status is measured by body mass index, or BMI (Hollander, De Roos, De Vries, & Teding Van Berkhout, 2005). BMI is tracked as percentiles and recorded on growth charts for pediatric patients (Centers for Disease Control and Prevention, 2000). BMI percentiles are considered more accurate than absolute BMI value in evaluating pediatric patients, as normal BMI value is variable in this age range (Borowitz, Baker, & Stallings, 2002).

Statement of the Problem

Long-term under-nutrition and its effects on weight and BMI have been acknowledged as problematic in CF care, according to Pencharz and Durie (1993). There is a “good correlation between the degree of malnutrition and the severity of pulmonary disease, which in turn adversely affected the survival” (Pencharz & Durie, 1993, p. 114).

Purpose and Significance

The purpose of this research was to determine what the adults with cystic fibrosis and the parents of children with cystic fibrosis perceive as barriers to nutrition education, and to determine their level of knowledge about nutrition education.

Advances in treatment have enabled CF patients to live into adulthood, with a “predicted median age of survival of 36.5 years” (CF Foundation, n.d.a, Paragraph 15). However, inadequate nutrient intake and the resultant malnutrition lead to increased

pulmonary problems and premature morbidity (Pencharz & Durie, 1993; Powers et al., 2002). The purpose of this study was to examine the needs of adults with cystic fibrosis and parents of children with cystic fibrosis with regard to nutrition education. The findings of the study will be used to refine the nutrition education offered in the CF Center of Idaho, and its results will be shared with other CF centers around the country.

Hypothesis/Research Questions

This experimental study will test the following research question:

Adults with cystic fibrosis and parents of children with cystic fibrosis will indicate no need for nutrition education in this survey.

Limitations

The limitations of this study include:

1. Possible lack of interest in completing the survey.
2. Uncontrolled-for variables, such as parent or patient illness, patient drop out, change of status including moving away from southwestern Idaho.

Delimitations

This research study will be delimited to adults with cystic fibrosis and parents of children with cystic fibrosis who are monitored through the CF Center of Idaho.

Assumptions

The following assumptions have been made for this research study:

1. Participants will complete the surveys honestly and correctly.
2. Adults with cystic fibrosis and parents of children with cystic fibrosis will clearly identify their education needs in this survey.

Definition of Terms

Cystic fibrosis: a genetic disorder that causes mucus from the pancreas, liver, lungs, reproductive organs, and sweat glands to be thicker than normal.

Body mass index: A measure of nutritional status that is the quotient of body weight in kilograms divided by height in meters squared.

CHAPTER II

Literature Review

This literature review provides a summary of information related to cystic fibrosis (CF) and nutrition, including physiological barriers, psychological barriers, and nutrient intake barriers to weight gain or weight maintenance. It also describes programs that have been tested to help improve nutrition education in this population.

History

Cystic fibrosis was first described as a disease in 1938; however, there are some indications of references to the condition in earlier historical accounts (Quinton, 1999). According to Quinton (1999), "A few references uncovered in medieval folklore predict death for an infant that tastes 'salty' when kissed" (Quinton, 1999, p. 4). Dr. Dorothy Hansine Andersen first described the involvement of the pancreas after conducting an autopsy on an infant who died of lung and digestive problems. She described the changes seen in the pancreas as fibrotic and coined the phrase "cystic fibrosis of the pancreas" (Quinton, 1999, p. 4).

Quinton (1999) describes the next decades of research performed as a quest for a hypothesis that accounted for the combined thickened mucus observed in the pancreas, intestines, and lungs, and the increased salt content noted in the sweat glands, along with other changes noted throughout the body. The joint presence of thickened mucus and increased salt content seemed to be important, however, the relationship between them

was unknown. The pancreas continued to be the main organ of interest, although the thick mucus excreted by the lungs was also extensively studied (Quinton, 1999). Years of investigation led to the development of the current model of CF disease, which describes CF as a disease of several body systems, all of which are affected by "electrolyte abnormalities and that mucus secretion is or becomes enhanced in some tissues but not others. It is clear that mutations in CF conductance transmembrane regulator (CFTR) gene directly affect chloride permeability" (Quinton, 1999, p. 14).

Quinton (1999) states that if untreated, over 90% of CF patients suffer from severe malnutrition due to the loss of pancreatic function and pancreatic enzymes. Other authors suggest that although the pancreatic enzymes play a role in determining the nutrition of the CF patient, malnutrition in this population is complex (e.g. Adde, Cardoso, & Rodrigues, 2004; Foster & Farrell, 1996; Pencharz & Durie, 1993; Stark, 2003).

Malnutrition as a Function of Chronic Illness

Nutritional status is often impaired in patients with chronic illnesses (Richardson & Davidson, 2003). This is thought to be due to disturbances in the energy equilibrium due to inflammation, according to Richardson and Davidson (2003). Inflammation may lead to increased calorie needs, and the presence of illness may lead to decreased calorie intake and lean tissue loss (Richardson & Davidson, 2003).

An energy imbalance such as that described above is observed in CF, according to Stark (2003), and leads to impaired nutritional status. Stark (2003) states that the energy imbalance is caused both by increased energy needs due to chronic lung disease or acute lung infection, and by increased energy loss due to malabsorption. Adde et al. (2004)

agree with this conclusion, and state that nutritional status is compromised by insufficient weight gain in CF patients as a consequence of energy imbalance, malabsorption, and decreased appetite.

In 1996, Foster and Farrell described other factors leading to malnutrition in CF patients. These factors included "presence and severity of pancreatic insufficiency, partial intestinal resection, if present, secondary to bowel obstruction (usually due to meconium ileus), growth rate, size of patient, severity of respiratory disease, macronutrient intake, micronutrient deficiencies, and liver disease" (Foster & Farrell, 1996, p. 238). They also described vomiting because of cough, regurgitation and abdominal pain as possible reasons why CF patients struggle with malnutrition. Pencharz and Durie (1993) also described factors such as liver disease, abnormal bile salt metabolism, and CF related diabetes as contributors to under-nutrition.

Malnutrition as a Function of Dietary Intake

Powers and Patton (2003) describe diet as the foundation of CF treatment. This treatment is not only connected to patients' growth, but also their survival over the long term. Many studies have suggested that infants, toddlers, and school age children with CF have lower than optimal calorie intake (Powers & Patton, 2003). Anthony, Bines, Paxton, & Phelan (1998) compared CF patients to their siblings to examine the relationship between eating and nutritional status. The CF patients were found to be significantly shorter and lighter than their healthy siblings were. According to Anthony et al. (1998), the CF patients ate more than their healthy siblings did, however, they did not eat the recommended amount of fatty foods.

The dietary recommendations for CF patients are to eat a high calorie (120 to 150% of the recommended number of calories) and high fat (35-40%) diet (Powers & Patton, 2003). However, Powers and Patton suggest that many CF patients do not achieve these goals. Adde et al. (2004) concurred, and suggested that the dietary recommendations be based on weight, and individualized for calorie and fat intake.

Powers and Patton (2003) also investigated the micronutrient intake of younger CF patients, and suggested that the younger CF patients ate foods that gave them more than 100% of the recommended intake daily for the vitamins A, C, and D. They noted, however, that low levels of zinc were found in CF patients, which "is an important mineral for growth, and in children with CF, zinc may be poorly absorbed" (Powers & Patton, 2003, p. 1623). Zinc deficiency is observed in malabsorption syndromes, according to Bromley (2000), and may lead to dysfunction in the taste and smell senses. Stark stated, "biological factors such as food palatability and satiety may inhibit dietary adherence in CF" (Stark, 2003, p. 794).

Malnutrition as a Function of Mealtime Behavior in Children

In addition to physical limitations, behavioral factors have been studied in CF children (Stark, 2003). Stark et al. (1997) observed mealtime factors and their impact on dietary intake. The CF patients were found to spend significantly more time at the dinner table and to have a slower eating pace. This was observed in school age and preschool children, and was reported to be very frustrating to the parents involved (Stark et al., 1997). Longer mealtimes were associated with increased parental reporting of behavior problems in general with their CF child, and with increased parental rating of the problematic eating behaviors. One problem with a slower eating pace is that a child who

eats more slowly will tend to eat less (Stark et al., 1997). Limiting mealtimes may seem counterintuitive; however, according to Stark et al. (1997), it is part of the behavioral treatment aimed at helping parents manage these difficulties at mealtimes.

Powers et al. (2002) studied mealtime behaviors in infants and toddlers, and found that CF patients demonstrated longer mealtimes. Toddler mealtimes for those with and without CF were compared, and the children with CF had significantly longer meals. As with the school age children, infants and toddlers were found to take in fewer calories than recommended, and fewer fat calories than recommended (Powers et al., 2002).

These findings were reinforced in another study of toddlers and preschoolers with CF conducted by Powers, Acton, et al. in 2005. They found that adequate growth was particularly critical in this age group, as "improved growth from 3 to 6 years of age is independently and positively predictive of better lung function at age 6" (Powers, Acton, et al., 2005, p. 1443). The educational intervention of Powers, Acton, et al. (2005) included counseling and behavioral components. Families were assigned three goals to improve, including increasing food intake, dosing pancreatic enzymes appropriately, and teaching parents mealtime skills. Families were questioned at three months and at 12 months. Difficulties in obtaining the diet diaries were noted, especially at the 12-month mark. The intervention group was compared to a second group, whose members received normal CF care at regular clinic visits. Powers, Acton et al. (2005) stated that the observed growth at the six month and 12 month periods in their experimental group was equivalent for children without CF, at the same age and gender.

Stark (2003) describes a series of studies that appear to show that parents of CF children are not confident in their ability to feed their children, and that they perceive

their children as having more maladaptive mealtime behaviors. The parents of CF children were also reported to demonstrate mismanagement of these behaviors (Stark, 2003). These behaviors were observed in infant, toddler, and school age CF children: Refusal or reluctance to eat, and various behaviors on the parents' part to encourage or even force eating (Stark, 2003).

CF Nutrition Programs

Researchers suggest that "nutrition education of the CF patient and family, involving nutrition information, correct use of enzymes, positive reinforcement of appropriate eating, and use of high-calorie supplements when indicated, may ensure that patients will achieve optimum nutrition therapy" (Adde et al., 2004, p. 476). Adde et al. (2004) assessed intensive, individual nutrition counseling among the CF patient, his or her family, and the CF clinic physician during their study. The patients and families were counseled by the same physician at each CF clinic visit for one year, and were supplied with information about nutritional issues. They found that patients who were considered slightly malnourished benefited most from individual education and monitoring. When they evaluated their study population and stratified it by age, they found the greatest improvement was in those younger than five years of age. They recommended that nutrition education be continued at the same level of intensity and individual counseling as in their study, stating "such a program is inexpensive and may prevent malnutrition, foster normal growth and weight gain, postpone the use of invasive intervention methods and possibly delay progression of lung disease" (Adde et al., 2004, p. 481).

Stapleton et al. (2001) studied the 'Go and Grow with CF' program in Australian CF patients and their caregivers over a period of four months. The 'Go and Grow with

CF' program is an intervention program aimed at caregivers of preschool and elementary school age children with CF, and at children alone in these age groups. They found that after the 'Go and Grow with CF' program, the children who had received the intervention demonstrated higher knowledge scores than the children in the control group, and caregivers who received the intervention demonstrated slightly higher knowledge scores than caregivers in the control group. Both of these scores were only increased in the short term, immediately after the intervention program (Stapleton et al., 2001). These increases were no longer noticeable at the one-year post-intervention mark. They concluded that the 'Go and Grow with CF' program was effective; however it needed to be part of an ongoing education program for families and patients.

Powers, Heidemann, Henry, Patton, and Stark (2005) described a new program for CF patients called CF Individualized Nutritional Assessment of Kids Eating, or CF INTAKE. CF INTAKE is modeled after diabetes education, and modified for CF. It evaluates calorie intake and number of meals eaten, fat intake, and enzyme usage. Patients and families in one study were visited at home, and provided tools to measure food and drink amounts and calorie intake. They found that the CF INTAKE program was a valid tool for targeting specific nutritional intervention, and for measuring progress (Powers, Heidemann, et al., 2005). However, the Powers, Heidemann, et al. (2005) study evaluated the reliability and validity of the CF INTAKE program, not the short-term or long-term effect of the program.

School aged children in two of Ireland's CF centers were the target of a qualitative study by Savage and Callery (2005). They interviewed 22 children and their parents separately to understand what members of each group thought of the topic of nutrition.

The two groups were found to have different perspectives. Parents were described as guarded about feeding their CF child a high fat diet if they were already gaining weight and growing adequately, and frustrated with the process if their children were not gaining weight. Children were indifferent to weight gain, and focused on having the energy to be active on a daily basis. Savage and Callery (2005) concluded that childrens' views must be considered as a part of the development of a dietary plan, and that the dietary plan must address the parents' views as well.

Nutrition education needs to continue into the adult years, as adults with CF must continue to be monitored for malnourishment (Yankaskas, Marshall, Rodman, Simon, & Sufian, 2004). Nutrition has been identified by adults with cystic fibrosis as one topic that they need more education about (Sawicki, McGuffie, Robinson, & Sellers, 2007). There is, however, a distinct lack of educational materials or programs for the adult CF population.

Summary

Despite advances in CF treatment, undernourishment remains a problem for CF patients in the United States (Adde et al., 2004). Researchers assert "the importance of nutritional status to the long-term survival and well-being of CF patients is well documented" (Adde et al., 2004, p. 476).

Powers, Heidemann, et al. (2005) stress the importance of individualized nutrition education for the CF patient. They recommend a program called CF INTAKE for nutrition education, and emphasize the importance of behavioral training to help increase dietary intake. Powers, Heidemann, et al. (2005) state the goal of nutrition for the pediatric CF patient is normal growth.

Although the nutrition status of CF patients is monitored at each CF clinic visit, researchers suggest "periodic assessment of the knowledge and self-management skills of children with CF and their parents may help identify deficits that need to be addressed to ensure that children are achieving optimum nutrition therapy" (Stapleton et al., 2000, p. 1494). It seems clear that input from patients and families must be considered when developing a nutritional education program, according to Savage and Callery (2005).

Nutrition education needs continue in the adult population (Sawicki et al., 2007). Adults with CF continue to be at risk for malnourishment, and identify nutrition as a topic requiring more education (Sawicki et al., 2007).

In the current study, a survey was used to assess the needs of adults with cystic fibrosis and parents of children with cystic fibrosis in regards to nutrition education. The surveys were distributed during routine CF clinic visits conducted over a three-month period. Adults with cystic fibrosis were asked to complete the adult survey, and parents of children with CF were asked to complete the parent survey. This study may lead to further investigation of adult nutrition education needs in the CF population, and refinement of the nutrition education offered at the St. Luke's CF Center of Idaho, including a proposed website for the center.

CHAPTER III

Method

The purpose of this study was to conduct a survey to assess the needs of adults with cystic fibrosis and parents of children with cystic fibrosis in regards to nutrition education. The surveys were distributed during routine CF clinic visits conducted over a three-month period. Adults with CF were asked to complete the adult survey, and parents of children with CF were asked to complete the parent survey.

Participants

Participants in the study were adult CF patients over the age of 18, and parents of CF patients under the age of 18. There were 35 participants in the survey, 18 who completed the adult survey and 17 who completed the parent survey. The participants were recruited from patients who attended the CF Center of Idaho in December 2008, January 2009, and February 2009. This study was conducted with the permission of the institutional review boards of St. Luke's Health Systems and Boise State University.

The mean age of the adult participant was 28.78 years, with a range of 18 to 49 years of age. The mean age of the parent participant was 31 years, with a range of 27 to 48 years of age. The majority of participants were female, with 10 adults and 14 parents identifying themselves as female.

The education levels reported by the adult survey participants included five high school graduates, seven who had attended some college, four college graduates, and two

who reported having master's degrees. Among the parent participants, two reported that they had attended some high school, four were high school graduates, six had attended some college, and five were college graduates.

In the parent participant population, six participants were parents of children aged one to four, seven participants were parents of children of school age (five to ten years of age), and four were parents of adolescents aged 11 to 17 years.

Design

The adults were asked to complete the adult survey, exhibited in Appendix B. The parents of CF children were asked to complete the parent survey, exhibited in Appendix C. Each participant gave informed consent before filling out the survey. The informed consent is found in Appendix D. The surveys were collected before each participant left clinic for the day, and each participant was thanked for his or her time.

Measurement Tools

Both the adult and parent survey included a Likert scale, with the value of 1 corresponding to "strongly agree" and the value of 5 corresponding to "strongly disagree." The majority of questions on each survey were answered with Likert scale response options. Participants were also asked to identify topics they would like more information on, and how they would like the information presented.

Procedure

Participants were recruited from the CF Center of Idaho, and were adults with CF or parents of children with CF. They were recruited from patients attending CF clinic in December 2008, and January and February 2009.

A letter describing the purpose of the study was distributed to every patient or parent of the patient who attended CF clinic in the months of December 2008, January 2009, and February 2009. The letter is included in Appendix A. Each potential participant was asked if he or she would be willing to complete a survey. Informed consent was then obtained, and any questions they had were answered by the primary investigator. The informed consent was collected, and the survey was then distributed. The primary investigator left the room while the survey was filled out. The survey was collected before the participant left clinic for the day. Potential participants who chose not to give informed consent were thanked for their time in reading the recruitment letter.

After the survey was collected, information was given to the staff of the CF Center of Idaho for use in developing a website and a nutrition education program, and relayed to the patients during a family education night sponsored by the CF clinic. The principal investigator presented the data and conclusions.

Statistical Analysis

The surveys were analyzed using the Statistical Package for Social Sciences (SPSS), version 14.0. Bivariate correlations and crosstabs were analyzed.

CHAPTER IV

Results

The following results are based on statistical and content analysis of survey questions. Participants completed an adult survey if they were cystic fibrosis patients over the age of 18. Participants completed a parent survey if they were the parent of a child with cystic fibrosis under the age of 18. Each of the survey questions included a Likert scale with the value of 1 corresponding to “strongly agree,” the value of 2 corresponding to “agree,” the value of 3 corresponding to “neutral,” the value of 4 corresponding to “disagree,” and the value of 5 corresponding to “strongly disagree.”

Participants

There were 35 participants in this survey. Of these 35, 18 completed the adult survey and 17 completed the parent survey. The majority of participants were female.

Height, Weight, and BMI

The first four survey questions assessed the participants’ knowledge of their or their child’s height, weight, BMI, and the importance of knowing the height, weight, and BMI. Most of the participants in both surveys agreed that they were told their height and weight or their child’s height and weight, with 16 adults (88.9%) and 15 parents (88.2%) agreeing or strongly agreeing that they were told this information in clinic. Two adults (11.1%) and one parent (5.9%) disagreed that they were told this information, and one parent (5.9%) was neutral.

The majority of participants agreed that knowing the height and weight of themselves or their child was important. Among the adult participants, nine (50%) strongly agreed and seven (38.9%) agreed that this information was important. Among the parent participants, 14 participants (82.3%) strongly agreed and two participants (11.8%) agreed that knowing their child's height and weight was important. Two adults (11.8%) and one parent (5.9%) disagreed with this question. The two variables "I am told height and weight" and "It is important to know height and weight" was highly correlated. In adults, Pearson correlation $r(18) = .929, p < .001$, and in parents, Pearson correlation $r(17) = .857, p < .001$.

The majority of adults reported that they were not told their BMI in clinic, with seven participants (38.9%) strongly disagreeing and five (27.8%) disagreeing that they were told their BMI. In contrast, the majority of parents reported that they were told their child's BMI in clinic, with nine participants (52.9%) strongly agreeing and three (17.6%) agreeing. Two of the adult participants (11.1%) and two of the parent participants (11.8%) were neutral. Three parent participants (17.6%) disagreed.

When asked if knowing their child's BMI was important, 10 parents (58.8%) strongly agreed and four (23.5%) agreed, two parents (11.8%) were neutral, and one (5.9%) disagreed. Eight adults (44.4%) agreed or strongly agreed that knowing their BMI was important, seven (38.9%) were neutral, and three (16.7%) disagreed or strongly disagreed. The statistical correlation between being told their BMI and "knowing my (or my child's) BMI is important" was significant only for the parents, with an $r(17) = .709$ and p value of .001.

When asked the next question “I am not sure why knowing my BMI is important,” five adults (27.8%) agreed or strongly agreed, four (22.2%) were neutral, and nine (50%) disagreed or strongly disagreed. Of the parents, one (5.9%) agreed with this statement, four parents (23.6%) were neutral, and 12 parents (70.6%) disagreed or strongly disagreed. The correlation between the questions of “knowing BMI is important” and “not sure why knowing BMI is important” was significant and negative in the adults, with $r(18)$ of -0.730 , $p = 0.001$. The correlation was not significant with the parents.

For parents who agreed that they were told their child’s BMI in clinic, the question of “I am not sure why knowing my child’s BMI is important” was statistically and negatively correlated, with $r(17) = -0.758$, $p < 0.001$.

Figure 1 shows the mean of the responses to the first four survey questions.

Figure 1: Mean Responses to Height, Weight, and BMI Questions

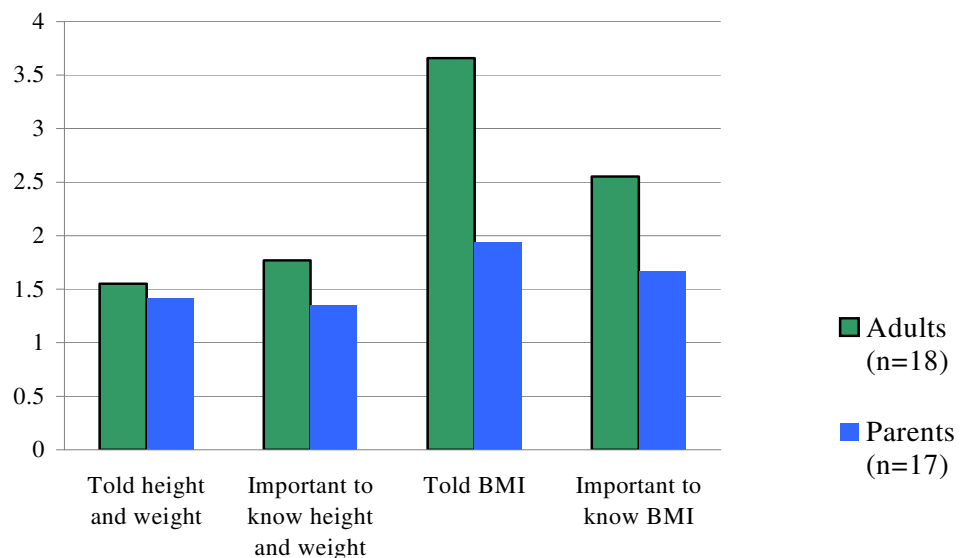
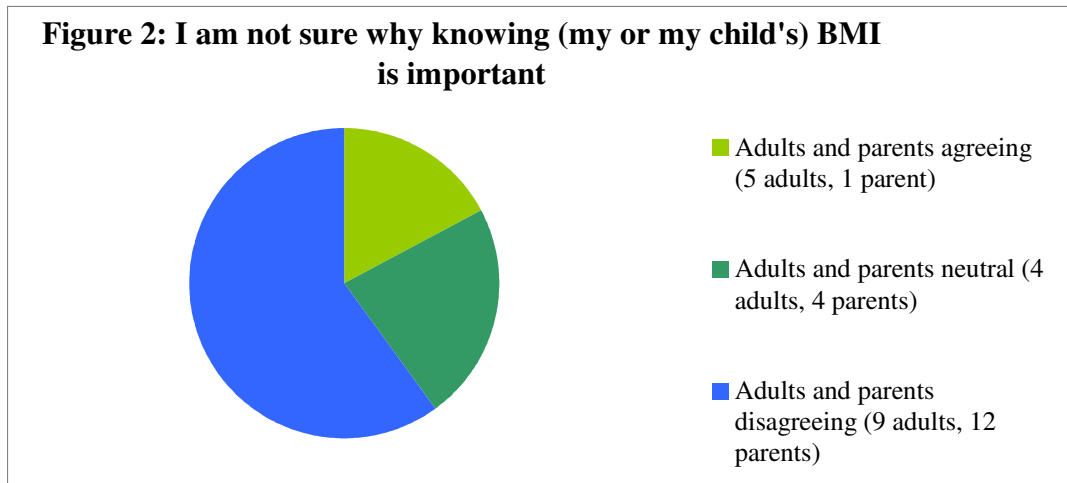


Figure 2 summarizes the responses for the question “I am not sure why BMI is important.”



Weight and Lung Function

Assessment of participant knowledge of the connection between weight and lung function was conducted through two survey questions. The participants were all asked to agree or disagree with the statement “There is a connection between my weight and my lung function.” This statement was amended to “my child’s” on the parent survey. The majority of adults, 14 (77.8%), strongly agreed or agreed that there was a connection between their weight and lung function. Three adult participants (16.7%) were neutral, and one adult (5.6%) strongly disagreed. The majority of parents also agreed or strongly agreed with this statement, with six parents (35.3%) strongly agreeing and eight (47.1%) agreeing. Three parents (17.6%) were neutral.

For the question “Maintaining a healthy weight is good for my lungs,” 11 adult participants (61.1%) strongly agreed, four (22.2%) agreed, two (11.1%) were neutral, and one (5.6%) strongly disagreed. On the parent survey, 12 parents (70.6%) strongly agreed

that achieving and maintaining a healthy weight was good for their child's lungs, four (23.5%) agreed, and one (5.9%) strongly disagreed.

The correlation in responses to these two questions was explored. Translating them into two variables, connection between weight and lung function, and achieving healthy weight and lung function, was not statistically significant for the parent group. However, correlation between these two variables was significant for the adults, with $r(18) = .856$ and $p < 0.001$.

The parents were also asked if they had questions about their child's growth, whether they were answered in CF clinic. Sixteen (88.9%) of the parents strongly agreed or agreed that their questions were answered. One parent (5.9%) strongly disagreed. A very strong correlation was found between the question about growth variable and the variables "told height and weight," with $r(17) = .915$ and $p < 0.001$, and "achieving healthy weight is good for lungs," with $r(17) = .945$ and $p < 0.001$ in the parent survey. The question about growth was not asked of the adults.

Calorie Intake and Energy Level

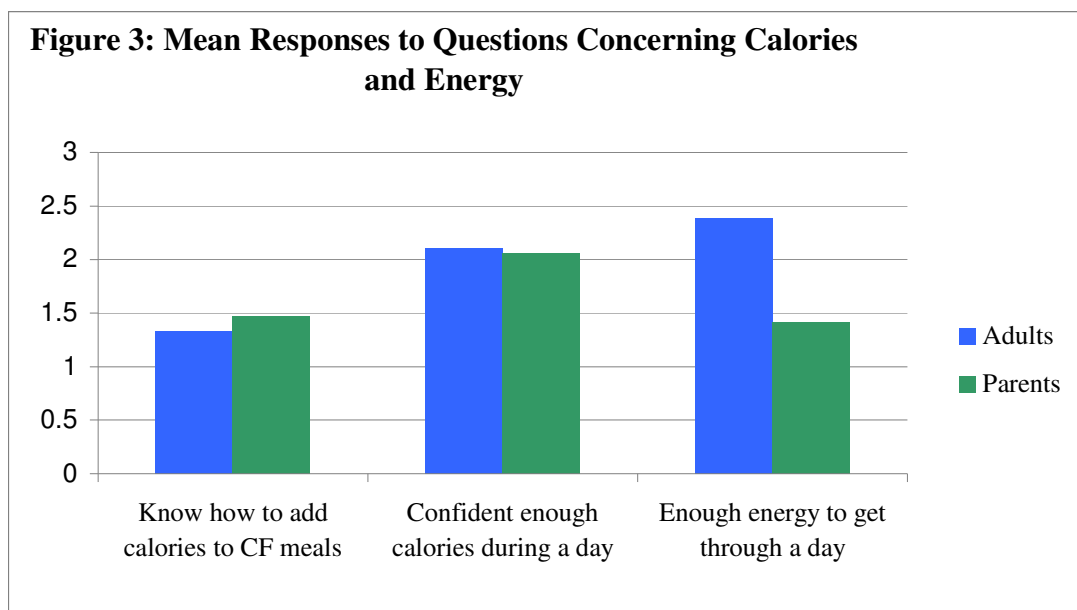
Adult and parent participants were asked about their calorie intake or their child's calorie intake, and their energy level, or their child's energy level. Each adult participant agreed that they knew how to add calories to their meals, with 12 (66.7%) strongly agreeing and six (33.3%) agreeing. The majority of parents felt they knew how to add calories to their child's meals, with 10 parents (58.8%) strongly agreeing and six (35.2%) agreeing with the statement. One parent (5.9%) was neutral with this statement.

Twelve adult participants reported that they were confident they consumed enough calories during the day, with six (33.3%) strongly agreeing and six (33.3%)

agreeing. Twelve parent participants agreed with that they were confident their child consumed enough calories during the day, with seven (41.1%) strongly agreeing and five (29.4%) agreeing. Four of the adult participants (22.2%) and three of the parent participants (17.6%) were neutral. Two adult participants (11.1%) and two parent participants (11.8%) disagreed that they were confident that they or their child consumed enough calories during the day.

Slightly more than half of the adult participants agreed that they had enough energy to make it through an average day, with four participants (22.2%) strongly agreeing and six participants (33.3%) agreeing. Six adult participants (33.3%) were neutral on this question, one adult participant (5.6%) disagreed, and one adult participant (5.6%) strongly disagreed. The majority of parents agreed or strongly agreed that their child had enough energy to make it through an average day, with 11(64.7%) strongly agreeing and five (29.4%) agreeing. One parent (5.9%) was neutral.

Figure 3 reviews this data.



There were no statistically significant correlations amongst the variables “know how to add calories,” “confident enough calories,” and “energy” in the adult survey. For the parents, the variables “know how to add calories” and “energy” were strongly correlated, with $r(17) = .762$ and $p < 0.001$. In addition, there was a correlation in the parent survey among the variables “know how to add calories,” “confident enough calories” and the variable “achieving healthy weight is good for lungs.” The correlation between “know how to add calories” and “achieving healthy weight is good for lungs” was significant, with $r(17) = .520$ and $p < .05$ as was the correlation “achieving healthy weight is good for lungs” and “confident enough calories” with $r(17) = .805$, $p < .001$.

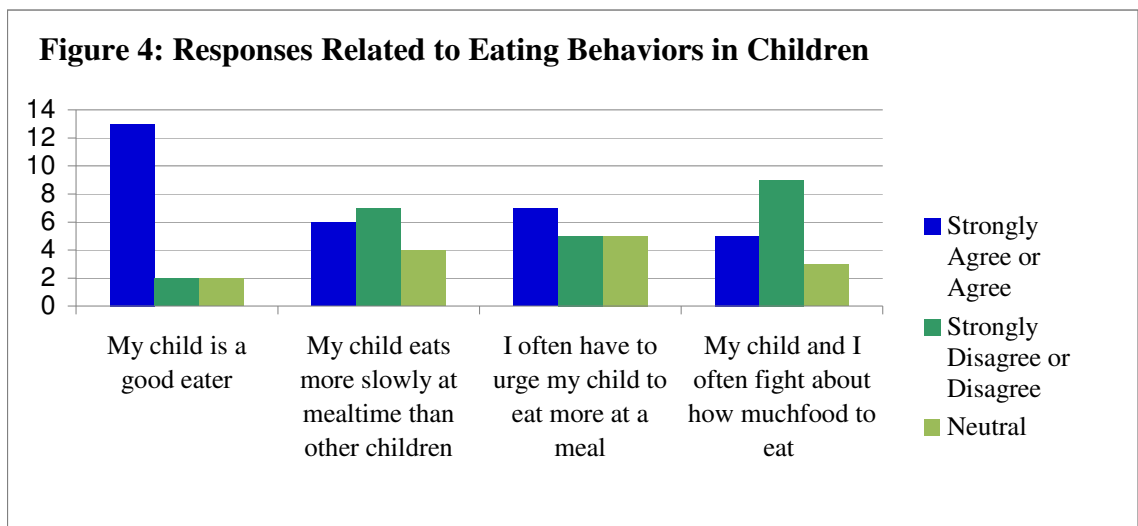
Eating Behaviors

The majority of adults reported that they do not need to be reminded to eat snacks or meals, with 11 participants (61.1%) strongly disagreeing or disagreeing that they needed to be reminded. Two adult participants (11.1%) strongly agreed, one adult (5.6%) agreed, and four adults (22.2%) were neutral about whether they needed to be reminded.

The majority of parents reported that they do not need to remind their child to eat snacks or meals, with 10 participants (58.8%) strongly disagreeing or disagreeing that they needed to remind their child to eat. Two parents (11.8%) strongly agreed, four (23.5%) agreed, and one (5.9%) was neutral that they needed to remind their child to eat.

Further parental attitudes with respect to how their child ate and their child’s mealtime behaviors were evaluated. The majority of parents felt their child was a good eater, with seven (41.1%) strongly agreeing and six (35.2%) agreeing. Two parents (11.8%) were neutral, and two parents (11.8%) disagreed that their child is a good eater. For the question “my child eats more slowly at mealtimes than other children do,” seven

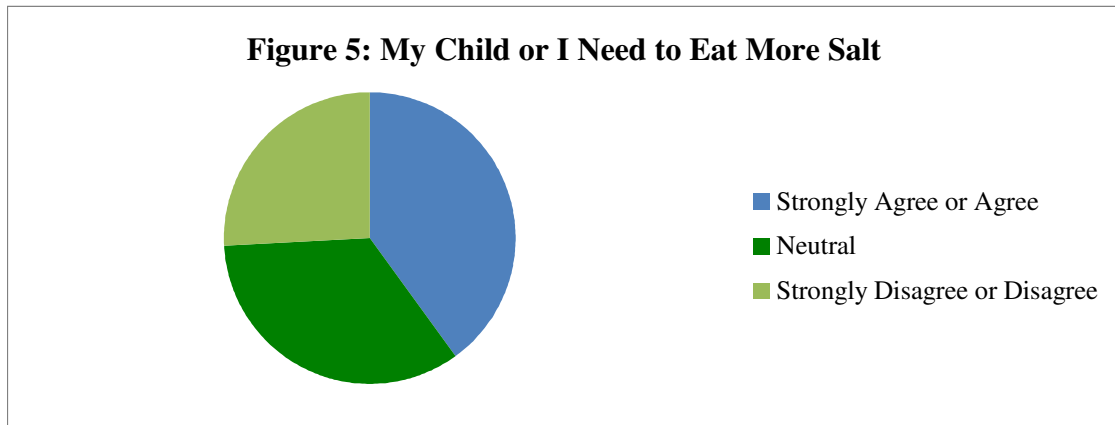
parents (41.1%) disagreed, four parents (23.5%) were neutral, four (23.5%) agreed, and two (11.8%) strongly agreed. Seven parents (41.1%) agreed or strongly agreed that they had to urge their child to eat more at a meal. Five parents (29.4%) were neutral, four parents (23.5%) disagreed, and one parent (5.9%) strongly disagreed that their child eats more slowly at mealtimes than other children. However, most parents reported not fighting with their child about how much food the child needs to eat, with nine parents (52.9%) disagreeing, three (17.6%) neutral, and five (29.4%) agreeing that they fought about how much their child needs to eat. Figure 4 summarizes this data.



Statistical correlations were not significant when the variable “good eater” was correlated with the variables “remind to eat,” “slow eater,” “urged to eat more,” and “fighting about eating.” There was a correlation between the variables “slow eater” and “fighting about eating,” with $r(17) = .539$ and $p < .05$. Fighting about eating was negatively correlated with the age of the child, with $r(17) = -.552$ and $p < .05$.

When asked if they needed to eat more salt, five adults (27.8%) strongly agreed, three (16.7%) agreed, and six (33.3%) were neutral. One adult (5.6%) participant disagreed and three adults (16.7%) strongly disagreed that they needed to eat more salt.

Five of the parent participants (29.4%) strongly agreed that their child needed to eat more salt, four (23.5%) agreed, six (35.3%) were neutral, and five (29.4%) parents disagreed, as shown in Figure 5.

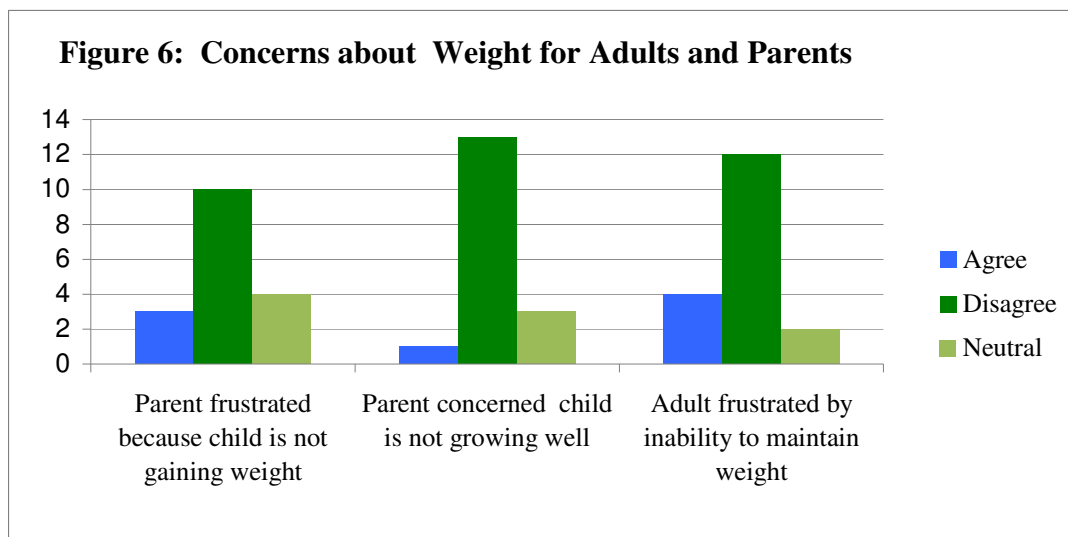


Weight Maintenance and Growth

Participants were asked about their feelings about weight maintenance. For the adults, the question was “I am frustrated because no matter what I do, I can’t maintain my weight.” The majority of adults disagreed with this question, with six participants (33.3%) disagreeing and six participants (33.3%) strongly disagreeing. One participant (5.6%) strongly agreed, three (16.7%) agreed, and two (11.1%) were neutral about whether they were frustrated about their weight maintenance.

Parent participants were asked about their feelings about their child gaining weight, or their concern about their child’s growth. For the parent question “I am frustrated because no matter what we do, my child doesn’t seem to be gaining weight,” the majority of parents disagreed, with eight parents (47.1%) disagreeing and two parents (11.8%) strongly disagreeing. Four parents (23.5%) were neutral. One parent (5.9%) strongly agreed and two (11.7%) agreed that they were frustrated their child was not gaining weight. Most of the parents denied concern that their child is not growing well,

with 13 parents (76.5%) disagreeing or strongly disagreeing with the statement, “I am concerned that my child is not growing well.” One parent (5.6%) agreed with the statement and three (17.6%) were neutral. No statistical correlations were found between the variables “concerned my child is not growing well” and “not gaining weight.” However, a statistical correlation was found between “not gaining weight” and “I am confident my child gets enough calories,” with $r(17) = -.512, p < .05$. Figure 6 summarizes concerns about weight.



Information Needs Assessment

The adult and parent participants were asked if they needed more information about nutrition or cystic fibrosis. Twelve adult participants disagreed that they needed more information about nutrition, with nine (50%) disagreeing and three (16.7%) strongly disagreeing. Four adult participants (22.2%) were neutral, one adult participant (5.6%) agreed, and one adult participant (5.6%) strongly agreed that they needed more information about nutrition. Ten parent participants disagreed that they needed more

information about nutrition, with nine (52.9%) disagreeing and one (5.9%) strongly disagreeing. Three parent participants (17.6%) were neutral, and four (23.5%) agreed that they need more information about nutrition.

A strong and negative statistical correlation was found in the adult population with “need information about nutrition” and the two variables “maintaining healthy weight good for lungs,” $r(18) = -.474$ and $p < .05$, and “important to know height and weight,” with $r(18) = -.479$ and $p < .05$. For parents, a strong and negative correlation was found between “need information about nutrition” and parent education, $r(17) = -.509$, $p < .05$, between “need information about nutrition: and “connection between weight and lung function,” with $r(17) = -.619$, $p < .01$, and between “need information about nutrition” and “achieving healthy weight is good for lungs,” $r(17) = -.612$, $p < .01$.

The majority of adult participants denied the need for information about cystic fibrosis in general, with 10 (55.6%) disagreeing and two (11.1%) strongly disagreeing. Four adult participants (22.2%) were neutral, and two adults (11.1%) strongly agreed that they needed more information about cystic fibrosis. Slightly less than half of the parents denied the need for information about cystic fibrosis in general, with eight (47.1%) disagreeing. Six parent participants (35.3%) were neutral, and three parent participants (17.6%) agreed that they needed more information about cystic fibrosis. There were no statistical correlations between the variables “need information about nutrition” and “need information about cystic fibrosis” in parent population, but a strong correlation existed in the adult population with $r(18) = .643$, $p < .01$.

Among the parents, a need for information about cystic fibrosis correlated strongly and negatively with the variables “confident my child gets enough calories,” with $r(17) = -.493$ and $p < .05$, and parent education, $r(17) = -.488$, $p < .05$, and positively with “frustrated because my child is not gaining weight,” with $r(17) = .656$, $p < .01$.

The parents and adults were asked if they could reach the CF clinic staff between clinic visits, and nine adults (50%) and 12 parents (70.6%) strongly agreed that they could reach staff in between visits. Seven adults (38.9%) and four parents (22.2%) agreed with the statement, one adult (5.6%) and one parent (5.9%) were neutral, and one adult (5.6%) disagreed.

CHAPTER V

Discussion

The purpose of this study was to develop a better understanding of nutrition education needs of adults with CF and parents of children with CF who receive their routine CF care from the CF Center of Idaho.

Nutrition education is provided at accredited CF clinics (CF Foundation, n.d.b). Adults and pediatric CF patients are monitored through quarterly visits at clinics such as the CF Center of Idaho. Height, weight, and BMI calculations are performed for each CF patient at every clinic visit. Nutrition status is measured by BMI (Hollander et al., 2005). BMI is tracked as BMI percentiles in the pediatric population, as BMI values are variable in this population (Borowitz, Baker, & Stallings, 2002).

The first four survey questions assessed the participants' knowledge of either their height and weight or their child's height and weight. Most of the participants agreed that they were told their height and weight or their child's height and weight. The majority of parents reported that they were told their child's BMI in clinic; however, the majority of adults reported that they were not told their BMI in clinic. The majority of participants agreed that knowing their BMI or their child's BMI was important. However, when the further probe question was asked, "I am not sure why knowing my BMI is important," nearly a third of the adult participants and one of the parent participants agreed. BMI is one assessment performed to assess nutritional status, with an adult BMI of less than 19

considered undernourished (Yankaskas et al., 2004). Children with a BMI percentile of less than the 25th are considered “at risk” for nutritional failure (Borowitz, Baker, & Stallings, 2002). Nutritional status is often impaired in patients with chronic illnesses (Richardson & Davidson, 2003). This is observed in CF patients, with their chronic lung disease as well as their malabsorption due to loss of pancreatic function (Quinton, 1999). BMI will therefore be a major focus of nutrition education in the CF Center of Idaho, especially in the adult population.

There is a correlation between malnutrition and increased pulmonary problems, and premature morbidity and mortality (Pencharz & Durie, 1993; Powers et al., 2002). Two survey questions assessed the participants’ knowledge of the connection between healthy weight and lung health. The majority of adult and parent participants agreed with the statements “there is a connection between my weight (or my child’s weight) and my (or my child’s) lung function” and “maintaining a healthy weight is good for my lungs (or my child’s lungs).” One parent strongly disagreed with the second statement, and one adult strongly disagreed with the first statement. The one parent who strongly disagreed with the statement about their child maintaining a healthy weight also disagreed with the statement “I am confident my child gets enough calories during the day.” This suggests that education on this topic needs to be ongoing.

Participants were also asked about calorie intake and energy levels. Each adult participant agreed that he or she knew how to add calories to his or her meals. The majority of parent participants agreed with that they knew how to add calories to their child’s meals. On the question of getting enough calories during the day, most of the adult and parent participants agreed with that they consumed enough calories. When

asked if they felt they had enough energy to get through an average day, just over half of the adults agreed, and the majority of the parents felt their child had enough energy to get through an average day.

Eating behavior assessment was a major goal of the survey. Not surprisingly, the majority of adults disagreed that they needed to be reminded to eat snacks or meals. The majority of parents also disagreed with the statement “I need to remind my child to eat meals or snacks.”

Parental attitudes with respect to how their child ate and their child’s mealtime behaviors were evaluated. The majority of parents reported thinking that their child is a good eater. The parents were evenly divided about whether their child eats more slowly than other children do. This question could have been refined to say, “my child’s mealtimes last 20 minutes or more,” to reduce perceived bias. In the CF child, longer mealtimes are often associated with lower calorie intake (Stark et al., 1997). There was a statistically significant correlation between the variables of “slow eater” and “often fight with my child about how much he or she should eat” suggesting that for some of the parents, mealtime behavior is an issue.

There was a negative correlation between the variables “fight with my child about how much he or she should eat” and the child’s age, suggesting that parents of older children were more often fought with their child about how much food the child should eat. Three of the parents of adolescent CF patients agreed with the statement, suggesting that the statement should be amended in the future to include clarification about the quantity of food.

Children and adults with CF should eat more salt, especially in the summer months, as they are at risk for low sodium levels (Borowitz, Baker, & Stallings, 2002). When asked if they agreed with the survey question “I (or my child) need(s) to eat more salt,” less than half the adult participants agreed, and half the parent participants agreed. The majority of both adult and parent participants were neutral on this question. This is an issue that should be included in education efforts in the future.

Achieving and maintaining a healthy weight is a struggle for some of the CF patients, and this was supported in this study. Although most of the adult participants disagreed with the statement “I am frustrated because no matter what I do, I can’t maintain my weight,” four adult participants agreed. When asked, “I am frustrated because no matter what we do, my child doesn’t seem to be gaining weight,” three parents agreed. A further question for the parents was “I am concerned that my child is not growing well;” only one parent agreed. Although only a small percentage of the participants indicated they were having problems achieving or maintaining a healthy weight, education on the topic of achieving and maintaining a healthy weight needs to continue to be provided at every clinic visit for every patient to ensure continual success in this area. Those who are at a healthy weight will be encouraged to keep their weight within a healthy range, and those who feel they are struggling with their weight or their child’s weight will be offered education to address those issues.

The final goal of the survey was to identify information needs in the adult and parent populations. When specifically asked if they needed more information about nutrition, the majority of adult and parent participants disagreed. However, two adult participants and four parent participants agreed. One of the adults who agreed that he or

she needed more information about nutrition disagreed that it was important to know his or her height and weight, suggesting a specific educational need. One of the adults who agreed that he or she needed more information about nutrition also disagreed that maintaining a healthy weight was good for his or her lungs, suggesting a second specific educational need. In the parent population, two parents who were neutral on the question “there is a connection between weight and lung function” agreed that they needed more information on nutrition, and one parent who disagreed with the question “achieving a healthy weight is good for lungs” agreed that he or she needed more information about nutrition.

When asked if they needed more information about cystic fibrosis, the majority of adult participants disagreed and half the parent participants disagreed. Two of the parents who agreed that they needed more information about cystic fibrosis disagreed with the statement “I am confident my child gets enough calories during the day.” They also agreed with the statement “I am concerned that my child is not gaining weight.” Of the three parents who agreed that they need more information about cystic fibrosis, one was a high school graduate and two were college graduates.

The CF Center of Idaho will continue to offer education to both populations on nutrition and cystic fibrosis at every clinic visit, as it is clear that this needs to be an ongoing process.

Conclusion

Nutrition education has been a focus of the CF Center of Idaho. This survey was performed to further investigate the education needs of the CF population.

Education issues identified include:

- Adult CF patients need to be informed of their BMI
- Adults with CF and parents of children with CF need to know why knowing their BMI is important and where the “at risk for nutritional failure” points are
- A connection needs to be made between healthy weight and healthy lungs
- Mealtime behavior in children needs to be focused on, especially for those parents of CF children who feel their child eats slowly
- Salt intake for CF patients should be emphasized, especially in summer

Helping the CF patient achieve and maintain a healthy weight is one of the keys to their continued good health, continued quality of life, and increased life span.

Education of the adult CF patient and the parent of the CF child must be an ongoing process. The CF Center of Idaho will focus on the issues identified in this survey over the next 12 months, and continue to focus on nutrition education as required by the CF Foundation.

REFERENCES

- Adde, F.V., Cardoso, A.L., & Rodrigues, J.C. (2004). Nutritional follow-up of cystic fibrosis patients: The role of nutrition education. *Jornal de Pediatria (Rio J)* 80, 475-482.
- Anthony, H., Bines, J., Paxton, S., & Phelan, P. (1998). Relation between dietary intake and nutritional status in cystic fibrosis. *Archive of Diseases in Childhood*, 78, 443-447.
- Borowitz, D., Baker, R.D., & Stallings, V. (2002). Consensus report on nutrition for pediatric patients with cystic fibrosis. *Journal of Pediatric Gastroenterology and Nutrition*, 35, 246-259.
- Bromley, S.M. (2000). Smell and taste disorders, a primary care approach. *American Family Physician*, 61(2), 427-436.
- Centers for Disease Control and Prevention, (2000). *Clinical growth charts*. Retrieved November 22, 2006, from http://www.cdc.gov/nchs/about/major/nhanes/growthcharts/clinical_charts.
- Cystic Fibrosis Foundation (n.d.a). *Frequently asked questions*. Retrieved November 6, 2006, from <http://www.cff.org/AboutCF/Faqs/>.
- Cystic Fibrosis Foundation (n.d.b). *Staying healthy*. Retrieved December 6, 2007, from <http://www.cff.org/LivingWithCF/StayingHealthy>.

- Foster, S.W., & Farrell, P.M. (1996). Enhancing nutrition in cystic fibrosis with comprehensive therapies (editorial). *Journal of Pediatric Gastroenterology and Nutrition*, 22(3), 238-239.
- Hollander, F.M., De Roos, N.M., De Vries, J.H., & Teding Van Berkhout, F. (2005). Assessment of nutritional status in adult patients with cystic fibrosis: Whole-body bioimpedance vs. body mass index, skinfolds, and leg-to-leg bioimpedance. *Journal of the American Dietetic Association*, 105(4), 549-556.
- Pencharz, P.B., & Durie, P.R. (1993). Nutritional management of cystic fibrosis. *Annual Review of Nutrition*, Retrieved Dec. 6, 2007 from <http://www.arjournals.annualreviews.org>.
- Powers, S.W., Acton, J.D., Daines, C., Ferguson, K.S., Jones, J.S., & Piazza-Waggoner, C. (2005). Randomized clinical trial of behavioral and nutrition treatment to improve energy intake and growth in toddlers and preschoolers with cystic fibrosis. *Pediatrics*, 116(6), 1442-1450.
- Powers, S.W., Byars, K.C., Jelalian, J., Mitchell, M.J., Mulvihill, M.M., Patton, S.R., et al. (2002). Calorie intake and eating behavior in infants and toddlers with cystic fibrosis. *Pediatrics*, 109(5), 75-86.
- Powers, S.W., Heidemann, M., Henry, R., Patton, S.R., & Stark, L.J. (2005). A tool to individualize nutritional care for children with cystic fibrosis: Reliability, validity, and utility of the CF Individualized Nutritional Assessment of Kids Eating (CF INTAKE). *Children's Health Care*, 34(2), 113-131.

- Powers, S.W., & Patton, S.R. (2003). A comparison of nutrient intake between infants and toddlers with and without cystic fibrosis. *Journal of the American Dietetic Association*, 103(12), 1620-1625.
- Quinton, P.M. (1999). Physiological basis of cystic fibrosis: A historical perspective. *Physiological Reviews*, 79 (Supplement 1), 3-22.
- Richardson, R.A. & Davidson, H.I.M. (2003). Nutritional demands in acute and chronic illness. *Proceedings of the Nutrition Society*, 62, 777-781.
- Sawicki, G.S., McGuffie, K., Robinson, W., & Sellers, D.E. (2007). Adults with cystic fibrosis report important and unmet needs for disease information. *Journal of Cystic Fibrosis*, 6(6), 411-416.
- Savage, E., & Callery, P. (2005). Weight and energy: Parents' and children's perspectives on managing cystic fibrosis diet. *Archives of Diseases in Childhood*, 90 249-252.
- Stapleton, D.R., Gurrin, L.C., Sherriff, J.L., Silburn, S.R., Sly, P.D., & Zubrick, S.R. (2001). The effect of "Go and Grow with CF" on nutrition and pancreatic enzyme knowledge of children with cystic fibrosis. *Australian Journal of Nutrition and Dietetics*, 58(3), 164-168.
- Stapleton, D.R., Gurrin, L.C., Sherriff, J. L., Silburn, S.R., Sly, P.D. & Zubrick, S.R. (2000). What do children with cystic fibrosis and their parents know about nutrition and pancreatic enzymes? *Journal of the American Dietetic Association*, 100(12), 1494-1500.
- Stark, L.J. (2003). Can nutrition counseling be more behavioural? Lessons learned from dietary management of cystic fibrosis. *Proceedings of the Nutrition Society*, 62, 793-799.

Stark, L.J., Bowen, A.M., Jelalian, E.J., Mulvihill, M. M., Powers, S.W., Tao, S., et al.

(1997). Descriptive analysis of eating behavior in school-age children with cystic fibrosis and healthy control children. *Pediatrics*, 99(5), 665-671.

Yankaskas, J.R., Marshall, B.C., Rodman, R., Simon, R.H., Sufian, B. (2004). Cystic fibrosis adult care. *Chest*, 125, 1S-39S.

APPENDIX A

Recruitment Letter



Dear CF Center of Idaho patient or family member,

The CF Center of Idaho is currently conducting research into nutrition education and the CF patient, in conjunction with Boise State University.

We are asking for your participation in this study. Please read the consent form attached to this letter.

Your participation is very important, however, it is voluntary. Participation in this study has no effect on your status, or your child's status, as a patient with the CF Center of Idaho. There are no negative consequences for participation or lack of participation.

The study is a survey, asking your opinion. You will be asked general demographic information, which will be kept confidential. There will be no personally identifying information on the survey.

We certainly hope that you will consider participating in this study, as it will help us shape our nutrition education in the CF Center of Idaho.

Sincerely,

Dixie Durham, RRT-NPS
CF Center of Idaho/Boise State University master's candidate

APPENDIX B

Adult Survey

Adult survey

For the following questions, please circle the number that most closely matches your experience or opinion, on a scale of one to five.

1. When I go to CF clinic, I am told what my height and weight is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

2. When I go to CF clinic, I am told what my body mass index (BMI) percentile is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

3. It is important to know what my height and weight is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

4. It is important to know what my body mass index (BMI) is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

5. There is a connection between my weight and my lung function.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

6. Maintaining a healthy weight is good for my lungs.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

7. I am not sure why knowing my BMI is important.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

8. I know how to add more calories to my meals.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

9. I am confident that I get enough calories during the day, even at work or school.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

10. I need to eat more salt.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

11. I have enough energy to make it through an average day.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

12. I have to be reminded to eat snacks or meals.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

13. I am frustrated because no matter what I do, I can't maintain my weight.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

14. I can easily reach the CF clinic staff in between clinic visits.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

15. I need more information about nutrition.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

16. I need more information about CF in general.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

17. I would like to get this information in one or more of the following ways (check all that apply): On a website_____

By phone_____

By mail_____

In a handout_____

In a newsletter_____

In a presentation_____

At a parent's night out_____

18. I would like to get more information on (please suggest a topic)

Now, please answer a few questions for demographic purposes:

My birthday is _____/_____/_____

I am (**circle one**) Male Female

The highest level of school I've completed is (**please circle one**):

- a) Some high school
- b) High school graduate or GED
- c) Some college
- d) College graduate
- e) Some graduate school
- f) Master's or higher degree

Thank you so much. We really appreciate your input.

APPENDIX C

Parent Survey

Parent Survey

For the following questions, please circle the number that most closely matches your experience or opinion, on a scale of one to five.

1. When I take my child to CF clinic, I am told what his or her height and weight is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

2. When I take my child to CF clinic, I am told what my child's body mass index (BMI) percentile is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

3. It is important to know what my child's height and weight is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

4. It is important to know what my child's body mass index (BMI) is.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

5. If I have questions about my child's growth, they are answered when my child and I attend CF clinic.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

6. There is a connection between my child's weight and his or her lung function.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

7. Helping my child achieve and maintain a healthy weight is good for his or her lungs.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

8. I am not sure why knowing my child's BMI is important.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

9. I know how to add more calories to my child's meals.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

10. I am confident that my child gets enough calories during the day, even if he or she is in day care or in school.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

11. My child needs to eat more salt.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

12. I think my child is a good eater.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

13. My child has enough energy to make it through an average day.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

14. I have to remind my child to eat snacks or meals.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

15. My child eats more slowly at mealtimes than other children do.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

16. I often have to urge my child to eat more at a meal.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

17. My child and I often fight about how much food he or she needs to eat.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

18. I am frustrated because no matter what we do, my child doesn't seem to be gaining weight.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

19. I am concerned that my child is not growing well.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

20. I can easily reach the CF clinic staff in between clinic visits.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

21. I need more information about nutrition and the CF child.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

22. I need more information about CF in general.

1	2	3	4	5
Strongly	Agree	Neutral	Disagree	Strongly
Agree				Disagree

23. I would like to get this information in one or more of the following ways (check all that apply):

On a website _____
By phone _____
By mail _____
In a handout _____
In a newsletter _____
In a presentation _____
At a parent's night out _____

24. I would like to get more information on (please suggest a topic)

Now, please answer a few questions for demographic purposes:

My birthday is _____/_____/_____

I am **(circle one)** Male Female

My child's age is **(please circle one)**:

- a) Under one year old
- b) One to four years old
- c) School age (five to ten years old)
- d) Adolescent (eleven to eighteen years old)
- e) Adult (over eighteen years old)

The highest level of school I've completed is **(please circle one)**:

- a) Some high school
- b) High school graduate or GED
- c) Some college
- d) College graduate
- e) Some graduate school
- f) Master's or higher degree

Thank you so much. We really appreciate your input.

APPENDIX D

Informed Consent

CONSENT FORM AND INFORMATION ABOUT

Survey of Adult Cystic Fibrosis Patients and Parents of Cystic Fibrosis Patients on Nutrition Education, a master's thesis project

To be conducted at: St. Luke's Cystic Fibrosis Center of Idaho
100 E. Idaho, Suite 200
Boise, ID 83712

Principal Investigator: Dixie Durham, RRT-NPS, MHS Candidate
100 E. Idaho, Suite 316
Boise, ID 83712
208-381-7334

INTRODUCTION:

You and your child are being asked to volunteer in a research study. The study will be a survey. 50 adults will complete the survey, and will be either adults with cystic fibrosis or parents of children with cystic fibrosis. Please carefully consider taking part in this research and discuss the study with your family, friends and personal physician. You are encouraged to ask questions to ensure you understand the procedures and risks involved. You should discuss anything that you do not understand with the person explaining it to you before you agree to volunteer. Once all of your questions have been answered, you may decide to participate or not participate.

It is important that you read and understand these general principles that apply to all who take part in this experimental research study:

- (a) Taking part in this study is entirely voluntary;
- (b) You may not benefit directly as a result of taking part in this study, but knowledge gained may be of benefit to others;
- (c) You are free to withdraw from the study at any time without affecting ongoing future care;
- (d) Leaving the study will not cause loss of any benefits to which you are otherwise entitled.

CF is a genetic disorder that primarily affects the lungs and the digestive systems of the body, causing breathing problems and problems digesting food. Due to these problems in digestion, malnutrition is a risk. Current dietary guidelines for adults and children with CF include a high calorie (120-150% of the recommended number of calories for children of the same age) and high fat (35-40% of calories from food) diet. Adherence to these guidelines may be difficult for a family. Previous studies have suggested that nutritional education is an important part of CF clinic care, and can lead to better dietary intake and growth.

I. Purpose

The purpose of this study is to help determine the nutrition education needs of the people who receive care at the CF Center of Idaho.

II. Study Procedures

You will be asked to fill out a survey. The survey will ask your opinion or experience with nutrition issues.

III. Risks/Side Effects/Discomforts

There is no known physical risk associated with this study. Focusing on nutrition and education may lead to increased stress in the person with CF, but this possibility is not considered likely. The primary investigator will be available to speak with or assist any participant or family experiencing undue stress.

IV. Benefits and Alternative Treatments

A. Benefits

There are no direct benefits to participating in this study.

B. Alternatives.

The alternative to participation in this study is to continue your current CF care.

V. Withdrawal/Voluntary Participation

Participation in this study is strictly voluntary and you have the right to refuse to participate in this research study or withdraw at any time without fear of anyone in the doctor's office or clinic getting mad at you, or changing your medical care because they are mad.

VI. Compensation

There is no compensation offered for this study.

VII. Confidentiality

If you consent to participate in this study, your personal health information will be kept confidential and will not be released without your permission, except as described in this paragraph or as required by law. As required by the Health Insurance Portability and Accountability Act of 1996, you will be asked for separate written permission (on a form called an "authorization") to use and disclose your personal health information for certain purposes related to the study. The only persons who will have access to identifying information will be the investigator, nurses, dietician, or social worker from the St. Luke's CF Center of Idaho. The results of the study may be published or presented at a

meeting or conference; however, no names or other identifying information will be used in any of these publications or presentations.

VIII. Acknowledgment

The primary investigator has answered my questions about my participation in this study. I understand that she is available to answer any further questions, along with Tedd McDonald, PhD., her advisor, whose phone number is 426-2425. I may also ask questions of the CF clinic director, Dr. Henry Thompson, at 381-7310. I understand I will be informed of any new findings that develop during the course of this research study that may relate to my willingness to continue to participate in this study. In case of a research related injury or problem, or a question regarding this study, I may reach the primary investigator, Dixie Durham, at 381-7334.

Should I have any additional questions about my rights as a research subject, they may be directed to the St. Luke's Health Systems IRB
190 E. Bannock Street
Boise, ID 83712
(208) 381-1406.

CONSENT TO PARTICIPATE

I have read all of the above, had the opportunity to ask questions, received answers concerning areas I did not understand, and willingly give my consent for participation in this study. I understand that a copy of the consent form I am signing will be returned to me.

Signature of Subject (if 18 or older)

Date

Signature of Parent or Legal Guardian

Date

Signature of Parent or Legal Guardian

Date

Signature of Person Obtaining Consent

Date

BOISE STATE UNIVERSITY GRADUATE COLLEGE

DEFENSE COMMITTEE AND FINAL READING APPROVALS

of the thesis submitted by

Dixie Lea Durham

Thesis Title: Survey of Adult Cystic Fibrosis Patients and Parents of Cystic Fibrosis Patients on Nutrition Education

Date of Defense: 01 April 2009

The following individuals read and discussed the thesis submitted by student Stephanie Stacey Starr, and they also evaluated her presentation and response to questions during the final defense. They found that the student passed the final defense, and that the thesis was satisfactory for a master's degree and ready for any final modifications that they explicitly required.

Tedd McDonald, Ph.D.

Chair, Supervisory Committee

Lonny Ashworth, M.Ed.

Member, Supervisory Committee

Jeff Anderson, M.Ed.

Member, Supervisory Committee

The final reading approval of the thesis was granted by Tedd McDonald, Ph.D., Chair of the Supervisory Committee. The thesis was approved for the Graduate College by John R. Pelton, Ph.D., Dean of the Graduate College.